

University of Dundee

Understanding Coeliac Disease

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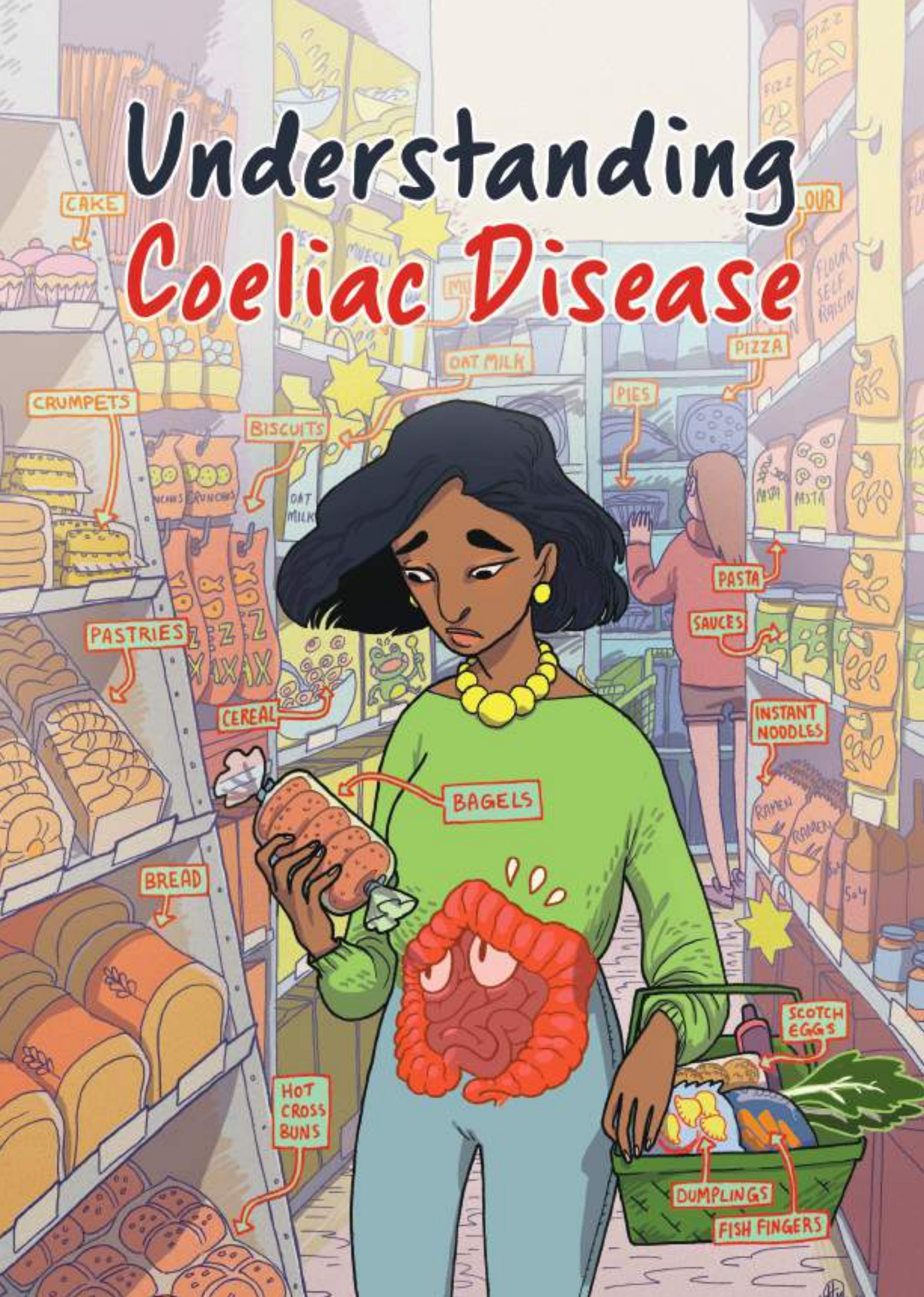
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Understanding Coeliac Disease



UNDERSTANDING COELIAC DISEASE

Edited by Chris Murray, Golnar Nabizadeh, and Phillip Vaughan



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Welcome to *Understanding Coeliac Disease*! This comic has been designed to raise awareness about coeliac disease among professionals, families, and communities. It includes a range of lived experiences with coeliac disease from the perspective of parents, children, adults, as well as a dietitian who specialises in the condition. The comic also provides some introductory information about coeliac disease, tips & facts, and resources for further reading.

This comic was produced in collaboration with Professor Jenny Woof from the School of Life Sciences at University of Dundee. In 2017, Jenny received the University's Stephen Fry award as Engaged Researcher of the Year in recognition of her outstanding work with schools and the public to raise awareness of various health-related topics and advances in the underlying science. Soon after, Jenny proposed a collaboration between the Schools of Life Science and Humanities on coeliac disease to help promote an understanding of the condition for the community. This built on an earlier public engagement project that started when Dana Hutton, then a pupil at Grove Academy, spent time in Jenny's lab as part of her Science Baccalaureate. The cross-School collaboration sparked a productive exchange between Life Sciences and Humanities as the project allowed specific areas of expertise to be brought into dialogue.

The comic would not have been possible without the stories of each contributor, and we thank them wholeheartedly for taking the time to share their experiences. We also thank the brilliant artists who brought the stories to life. Special thanks to Rebecca Horner for her teamwork and production on this comic, as well as to Chris Murray and Phillip Vaughan for their feedback and editorial work. Extra special thanks to Myles Fitt and Coeliac UK; Myles was a tireless partner on this comic and provided expert guidance every step of the way. Thank you, Myles!



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Scripts edited by Myles Fitt
Front cover by Letty Wilson
Back cover by Helen Robinson
Production by Rebecca Horner



What is COELIAC DISEASE?

ART BY ASHLING LARKIN



COELIAC DISEASE (PRONOUNCED SEE-LIAC) IS A LIFELONG AUTOIMMUNE CONDITION WHERE THE BODY'S IMMUNE SYSTEM REACTS TO GLUTEN, A PROTEIN FOUND IN WHEAT, BARLEY AND RYE. SOME PEOPLE ARE SENSITIVE TO OATS TOO.



THE BODY'S REACTION TO GLUTEN CAUSES DAMAGE TO THE LINING OF THE INTESTINE, THE PLACE WHERE FOOD AND NUTRIENTS ARE ABSORBED.

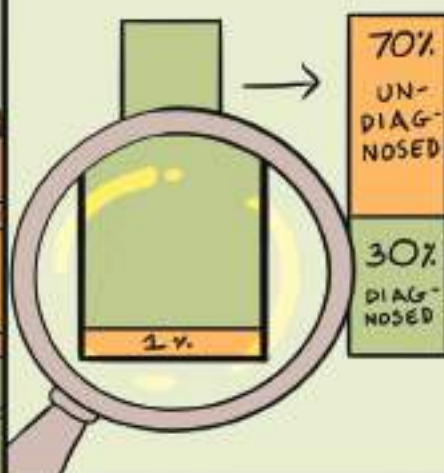
THIS DEPRIVES THE BODY OF THE NUTRIENTS IT NEEDS, AND CAN LEAD TO MALNUTRITION.



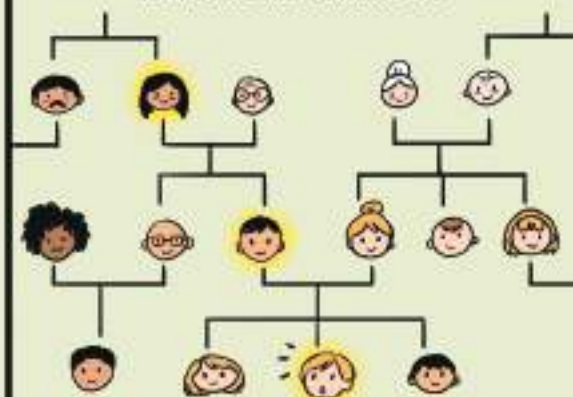
PEOPLE WITH UNDIAGNOSED COELIAC DISEASE CAN HAVE A WIDE RANGE OF SYMPTOMS. MANY OF THE SYMPTOMS ARE RELATED TO THE DAMAGE IN THE GUT, WHILE OTHERS ARE THE RESULT OF THE BODY BEING STARVED OF NUTRIENTS, WHICH CAN LEAD TO FATIGUE AND ANAEMIA.



AROUND 1% OF THE UK POPULATION HAS COELIAC DISEASE, BUT ONLY 30% OF THOSE WITH THE CONDITION HAVE BEEN DIAGNOSED.



WHILE COELIAC DISEASE AFFECTS AROUND 1 IN 100 PEOPLE IN THE UK, IT IS A GENETIC CONDITION.



THIS MEANS THAT IF YOU HAVE AN IMMEDIATE FAMILY MEMBER (PARENT, SIBLING OR CHILD) WHO HAS COELIAC DISEASE, THEN YOUR CHANCES OF HAVING THE CONDITION INCREASES TO 1 IN 10.

ON AVERAGE, 1 IN 4 PEOPLE DIAGNOSED WITH COELIAC DISEASE WERE PREVIOUSLY MISDIAGNOSED WITH IRRITABLE BOWEL SYNDROME (IBS) AS THE SYMPTOMS OFTEN LOOK SIMILAR SUCH AS STOMACH CRAMPS, BLOATING, DIARRHOEA, CONSTIPATION AND EXHAUSTION.

COELIAC DISEASE? IBS?



IF YOU'VE BEEN DIAGNOSED WITH IBS IN THE PAST, STILL HAVE SYMPTOMS, AND HAVEN'T BEEN CHECKED FOR COELIAC DISEASE BEFORE, YOU SHOULD ASK TO BE TESTED. MAKE SURE YOU ARE EATING ENOUGH GLUTEN IN YOUR DIET SO THE TEST WORKS.

OVER THE PAGE, YOU'LL MEET SOME PEOPLE WHO SHARE THEIR EXPERIENCE OF COELIAC DISEASE, LEARN SOME HELPFUL TIPS FOR MANAGING THE CONDITION, AND FIND OUT WHERE YOU CAN TURN FOR MORE RESOURCES ON THE SUBJECT.

FOR THOSE WHO THINK THEY MAY HAVE COELIAC DISEASE, CHECK OUT COELIAC UK'S ONLINE ASSESSMENT CALLED 'IS IT COELIAC DISEASE?' SYMPTOMS ARE ASSESSED AND, UPON COMPLETION, ADVICE WILL BE GIVEN AS TO WHETHER FURTHER TESTING IS REQUIRED FROM A GP.

WWW.ISITCOELIACDISEASE.ORG.UK

LYNSEY'S DIAGNOSIS STORY

ART BY CATRIONA LAIRD

I'M LYNSEY.
I WAS DIAGNOSED
WITH COELIAC DISEASE
12 YEARS AGO WHEN
I WAS 20.



WHAT ARE THE SIGNS OF COELIAC DISEASE?

PEOPLE WITH COELIAC DISEASE CAN HAVE A RANGE OF SYMPTOMS: FREQUENT BOUTS OF DIARRHOEA, NAUSEA, FEELING SICK AND VOMITING, STOMACH PAIN AND CRAMPING, GAS AND BLOATING, REGULARLY FEELING TIRED AND ONGOING FATIGUE, ANAEMIA, WEIGHT LOSS, REGULAR MOUTH ULCERS, CONSTIPATION OR HARD STOOLS, OR SKIN RASH.

ANAEMIA,
THAT'S ME.



I GET
STOMACH CRAMPS
A LOT.



I REGULARLY
HAVE DIARRHOEA BUT
DON'T KNOW WHY.



YOU KNOW, IF YOU
KEEP HAVING THESE SYMPTOMS
REGULARLY, YOU SHOULD SEE YOUR
GP AND ASK TO BE TESTED FOR
COELIAC DISEASE.



HOW LONG DID IT TAKE
FOR YOU TO BE DIAGNOSED WITH
COELIAC DISEASE?



WELL, IT WASN'T AS
STRAIGHTFORWARD AS I WOULD
HAVE LIKED...



WHEN I WAS 20, I STARTED TO FEEL UNWELL. MY MUM, ALREADY HAD COELIAC DISEASE AND EVEN THOUGH NONE OF MY SYMPTOMS MATCHED HERS, WE WERE WORRIED THAT IT MAY BE GENETIC. THAT'S WHEN I DECIDED TO GET TESTED.



MY INITIAL TEST RESULTS CAME BACK NEGATIVE. I WAS DIAGNOSED WITH IRRITABLE BOWEL SYNDROME (IBS). IBS HAS SIMILAR SYMPTOMS TO COELIAC DISEASE.



I WENT TO THE DOCTOR A COUPLE OF TIMES. THEY GAVE ME MEDICINE FOR IBS TO STOP SPASMS BUT MY SYMPTOMS KEPT GETTING WORSE.



I ASKED FOR ANOTHER BLOOD TEST.

I THINK IT'S JUST STRESS. I CAN TELL JUST LOOKING AT YOU THAT YOU DON'T HAVE COELIAC DISEASE.



OKAY, IF IT HELPS, LET'S RUN ANOTHER TEST.



THIS TIME, THE TEST RESULTS CAME BACK POSITIVE!
AFTER AN ENDOSCOPY, IT WAS CONFIRMED THAT
I HAVE COELIAC DISEASE.



MY CASE ISN'T THAT UNUSUAL.
1 IN 4 PEOPLE WITH COELIAC DISEASE ARE
MISDIAGNOSED WITH IBS. PEOPLE WITH IBS
SHOULD GET TESTED FOR COELIAC DISEASE
IF THEY HAVEN'T ALREADY.



MAYBE
I'LL CUT OUT
GLUTEN.

ACTUALLY, YOU SHOULD
MAKE SURE THAT YOU KEEP EATING
GLUTEN UNTIL YOU HAVE A DIAGNOSIS.
OTHERWISE THE TESTS WON'T
BE ACCURATE.

IT'S IMPORTANT THAT GPs
SPOT THE SYMPTOMS QUICKLY, BUT
ALSO THAT PEOPLE WITH SYMPTOMS GO
TO THE GP QUICKLY TOO. THE SOONER
YOU CAN GET A DIAGNOSIS
THE BETTER.



IT'S GREAT TO HAVE A
DIAGNOSIS NOW, BECAUSE IT
MEANS THAT I CAN LOOK AFTER
AND RESTORE MY HEALTH.

I'M ALSO LUCKY TO
HAVE SUPPORTIVE FRIENDS, FAMILY
AND COLLEAGUES



IT'S IMPORTANT THAT
WE EDUCATE OURSELVES
ABOUT COELIAC DISEASE,
AND THERE ARE LOTS OF
GREAT RESOURCES OUT
THERE.



FOR MORE INFORMATION ON RESOURCES PLEASE SEE P.19 OF THIS COMIC

SIMON O'LOUGHLIN & FAMILY

ART BY REBECCA HORNER



PREPARATION IS KEY. WE PREPARE FAMILY MEALS IN ADVANCE, AND THINK ABOUT MEAL PROVISION FOR TRIPS, HOLIDAYS, AND EATING OUT.



EATING FRESH FOOD RATHER THAN PROCESSED MEALS IS THE HEALTHIEST WAY TO STAY GLUTEN FREE.

MY COLLEAGUES AT WORK KNOW NOT TO OFFER ME DONUTS OR BISCUITS. THEY BRING IN GLUTEN FREE TREATS FOR ME TOO.



MY WORK TAKES ME OUT OF THE OFFICE A LOT, SO WHEN I TRAVEL I MAKE SURE TO HAVE SNACKS WITH ME IN CASE I CAN'T FIND ANYWHERE SAFE TO EAT.



MOST MEETINGS I NEED TO ATTEND ASK FOR DIETARY REQUIREMENTS BEFORE THE EVENT. SOMETIMES I'LL GET A FAR BETTER LUNCH THAN EVERYONE ELSE, BUT OTHER TIMES I'LL JUST GET FRUIT.

WHY DON'T YOU TRY THE SANDWICHES? THEY'RE GREAT!



SO LONG AS I'M SAFE, I DON'T MIND.

DON'T BE AFRAID TO CHALLENGE DOCTORS IF YOU SUSPECT YOU HAVE COELIAC DISEASE. I WAS MISDIAGNOSED AS HAVING IRRITABLE BOWEL SYNDROME BEFORE A DOCTOR TESTED ME PROPERLY.

THIS DELAY MEANT I DEVELOPED OSTEOPOROSIS, ANOTHER SERIOUS HEALTH CONDITION.









NIAMH'S SCHOOL STORY

ART BY ASHLING LARKIN



EATING OUT: ALISON'S STORY



ART BY ASHLING LARKIN

I OPENED ROSEANGLE KITCHEN CAFE AS MY DAUGHTER HAS COELIAC DISEASE AND I WANTED HER TO HAVE A SAFE, HASSLE-FREE OPTION FOR EATING OUT.

EATING OUT CAN BE CHALLENGING FOR MY DAUGHTER AND OTHERS WHO HAVE COELIAC DISEASE.



EVERY TIME SOMEONE WITH COELIAC DISEASE EATS OUT, THEY ARE PLACING TRUST IN SOMEONE ELSE MAKING THEIR FOOD.

THEY RISK BECOMING VIOLENTLY SICK AND UNWELL FOR SEVERAL DAYS IF THEIR MEAL CONTAINS GLUTEN – EVEN A CRUMB.

THEY MAY NEED TO PLAN AHEAD EVERY TIME. NOT ALL VENUES HAVE GLUTEN FREE OPTIONS AND THERE MAY BE A RISK THAT SOME DO NOT PROPERLY UNDERSTAND THAT GLUTEN FREE FOOD REQUIRES CAREFUL PREPARATION TO AVOID CROSS CONTAMINATION.

WHEN GOING TO NEW VENUES, THEY NEED TO SPEND TIME CHECKING THAT THEY CAN PROVIDE GLUTEN FREE OPTIONS, AND THAT THEY CAN RELY ON THIS OPTION.

WHEN AT A VENUE, MY DAUGHTER NEEDS TO SPEAK UP AND BE PREPARED TO ASK QUESTIONS ABOUT THE INGREDIENTS IN DISHES, AND TO ASK HOW MEALS ARE PREPARED.



IS THIS PREPARED IN A SEPARATE FRYER?

SHE NEEDS TO TRUST THAT THE WAITING STAFF ARE CORRECTLY TAKING HER ORDER AND SERVING HER MEAL, AND THEN CONFIRM THAT SHE IS BEING SERVED THE GLUTEN FREE DISH.



IS THIS THE GLUTEN FREE DISH?

IF SHE IS OUT ENJOYING HERSELF WITH FRIENDS OR COLLEAGUES WHO DECIDE ON SPUR OF THE MOMENT TO GO TO A VENUE WHICH SHE ISN'T FAMILIAR WITH, SHE NEEDS TO QUICKLY WORK OUT IF IT PROVIDES SAFE GLUTEN FREE OPTIONS.



OK, IF THIS VENUE DOESN'T DO GLUTEN FREE I'LL NEED TO THINK OF AN ALTERNATIVE PLAN. SOME QUICK ONLINE RESEARCH WILL HELP.

SO, MY OPTIONS ARE POLITELY DECLINE AND EAT AT HOME; GO IN BUT JUST HAVE A DRINK; OR TAKE FRIENDS TO A COELIAC UK ACCREDITED GLUTEN FREE VENUE THAT I FOUND ONLINE.



PROVIDING SAFE, GLUTEN FREE OPTIONS ISN'T DIFFICULT - PROVIDED YOU FOLLOW THE RIGHT STEPS. HERE ARE SOME OF MY TIPS!

FIRSTLY, CHOOSE AND USE THE RIGHT INGREDIENTS.



SAFE PREPARATION AND COOKING
OF GLUTEN-FREE FOOD.

GLUTEN-
FREE ONLY!

EFFECTIVE CLEANING AND GOOD
PERSONAL HYGIENE.

WOULD YOU
LIKE THE GLUTEN-
FREE OPTION?

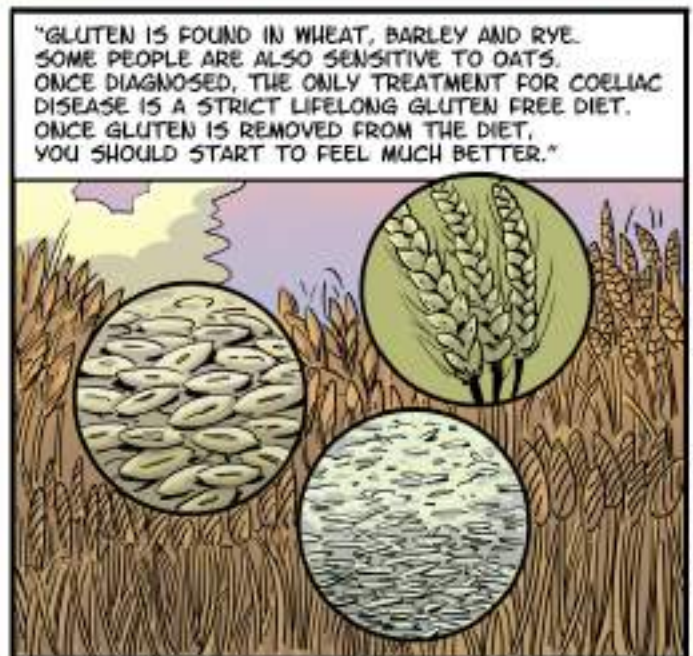
SERVING GLUTEN-FREE MEALS;
COMMUNICATING CLEARLY WITH CONSUMERS
IS ESSENTIAL.

CLEARLY LABELLING YOUR MENUS.

STAFF TRAINING ON ALLERGENS.

EDUCATING YOUR STAFF
IS ALSO REALLY IMPORTANT.

IT'S REALLY
SATISFYING MEETING
THE NEEDS OF
CUSTOMERS, WHO ARE
VERY APPRECIATIVE
OF HAVING SOMEWHERE
THEY CAN SAFELY EAT
AND RELAX. THEY COME
BACK AGAIN AND AGAIN
ONCE THEY KNOW WE
CAN SAFELY LOOK AFTER
THEIR GLUTEN FREE
DIET.



"YOU HAVE TO HAVE THE RIGHT GENETIC MAKE UP TO GET COELIAC DISEASE."

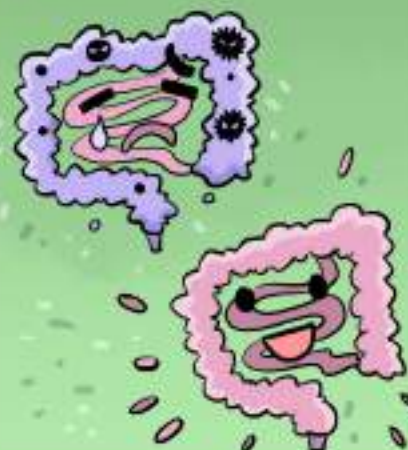
"IF YOU HAVE COELIAC DISEASE, THERE IS A 1 IN 10 CHANCE THAT AN IMMEDIATE RELATIVE MAY ALSO HAVE THE CONDITION."

ATTENTION

IF YOU THINK YOU MAY HAVE COELIAC DISEASE, DO NOT REMOVE GLUTEN UNTIL A DIAGNOSIS IS MADE.



"YOU WILL START TO FEEL BETTER ONCE YOU BEGIN TO AVOID GLUTEN BUT IT TAKES TIME FOR THE GUT TO FULLY HEAL. IT VARIES BETWEEN PEOPLE BUT IT CAN BE UP TO 5+ YEARS."



"THERE ARE MANY NATURALLY GLUTEN FREE FOODS AVAILABLE."



"MANY PROCESSED FOODS ARE GLUTEN FREE. TAKE TIME TO READ THE LABELS CAREFULLY."

"LEARN BASIC COOKING TECHNIQUES SO YOU CAN COOK WITH FRESH INGREDIENTS."



"BY LEARNING SOME USEFUL TIPS YOU CAN ENJOY A RICH AND VARIED GLUTEN FREE DIET!"



HERE are SOME TIPS FOR people WITH COELIAC disease, THEIR family & FRIENDS (THANKS Lynsey!)



If you are looking for support on coeliac disease there are lots of sources such as the Coeliac UK website, and various social media pages where you can post questions and talk to other people with the condition.



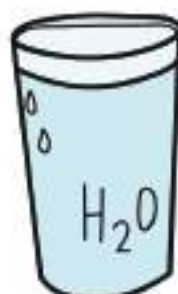
Be organised!
Batch cook meals and have convenient snacks on hand



When travelling, consider where you'll be staying and take gluten free bread and other essentials, as needed.



When eating out, call venues in advance to ensure they offer gluten free options. Also check they know the importance of preparing gluten free food safely, free of cross-contamination.



If you are 'glutened', drink plenty of water.



Rely as much as possible on naturally gluten free foods.

FURTHER RESOURCES



Coeliac UK

www.coeliac.org.uk

To join Coeliac UK

coeliac.org.uk/join-us/ or call **0333 332 2033**

Symptoms

coeliac.org.uk/coeliac-disease/about-coeliac-disease-and-dermatitis-herpetiformis/symptoms/

Online Symptom Assessment

isitcoeliacdisease.org.uk

Getting Diagnosed

coeliac.org.uk/coeliac-disease/getting-diagnosed/

Coeliac Disease in Children

coeliac.org.uk/coeliac-disease/coeliac-disease-in-children/



Coeliac Disease in School

coeliac.org.uk/gluten-free-diet-and-lifestyle/school-meals/

Gluten Free Diet

coeliac.org.uk/gluten-free-diet-and-lifestyle/

Gluten Free Recipes

coeliac.org.uk/gluten-free-diet-and-lifestyle/recipe-database/



Eating Out

coeliac.org.uk/gluten-free-diet-and-lifestyle/eating-out/

Venue Guide

coeliac.org.uk/gluten-free-diet-and-lifestyle/venue-guide/

Coeliac UK Accredited Venues

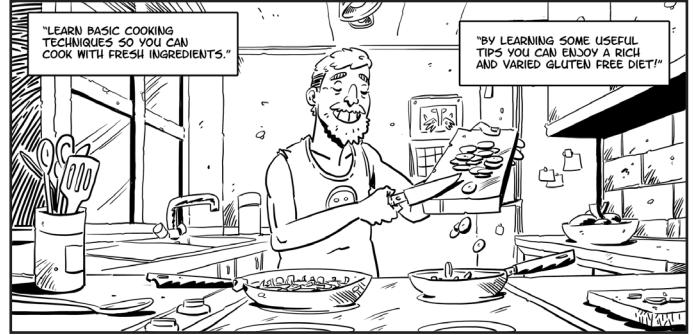
coeliac.org.uk/gluten-free-diet-and-lifestyle/eating-out/eat-out-with-confidence-at-our-gf-accredited-venues/

Support for the Food Industry

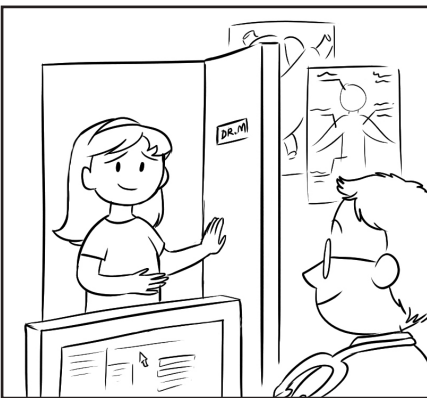
www.coeliac.org.uk/food-industry-professionals/

PROCESS

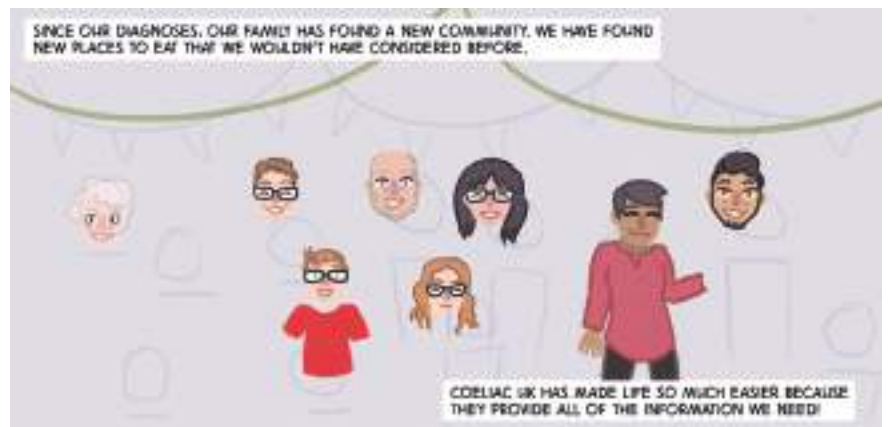
A Dietitian's Perspective. Art by Norrie Millar. Traditional pencils, scanned and inked digitally.



What is Coeliac Disease?
Art by Ashling Larkin. Roughs, inks, and finished colour.



Simon O'Loughlin & Family. Art by Rebecca Horner.
Layouts, in-progress stage, and finished panel.



Understanding Coeliac Disease. Art by Letty Wilson and Helen Robinson.
Helen's design sheet for the back cover, referencing Letty Wilson's front cover and character design.



CONTRIBUTOR BIOS



Golnar Nabizadeh is Lecturer in Comics Studies at the University of Dundee. Her research focuses on comics and visual studies and particularly on representations of trauma, migration, and memory in these fields. She is the author of *Representation and Memory in Graphic Novels* (2019), published by Routledge.



Rebecca Horner is a cartoonist and colourist who is constantly working on several projects at once. She is Workshop Lead at Dundee Comics Creative Space and has done production on many books, including this one! rebeccahorner.com



Catriona Laird is an illustrator and comic artist and when she's not drawing webcomics and designing characters she's thinking about drawing webcomics and designing characters. Catriona is also a freelance designer for V&A Dundee helping facilitate design workshops and tours for groups of all ages and abilities.



Ashling Larkin is a freelance comic artist & illustrator based in Dundee. She has been part of a number of University Publications and is currently working on her personal project, *The Enchanted Book*. You can find more of her work on her website: ashlingdraws.com



Norrie Millar is a Scottish comics artist based in Dundee. He self-publishes his own work and is also a freelance illustrator, providing work for numerous companies and publishers. behance.net/norriemillar



Katie Quinn is an illustrator and comic book artist based in Edinburgh. Her work has been exhibited and sold around the UK and published in the likes of *Counterpoint Magazine* and *Wilma*, Ink Pot Studio's anthology of girls' comics. Her illustration clients include Royal Botanic Gardens Edinburgh and Cranachan Publishing. oohkatieq.co.uk



Helen Robinson is a comics artist and illustrator from Northern Ireland. She has recently had work published in international anthologies such as *Wayward Sisters* and *Shout Out!* You can find her work at gofishblues.com.

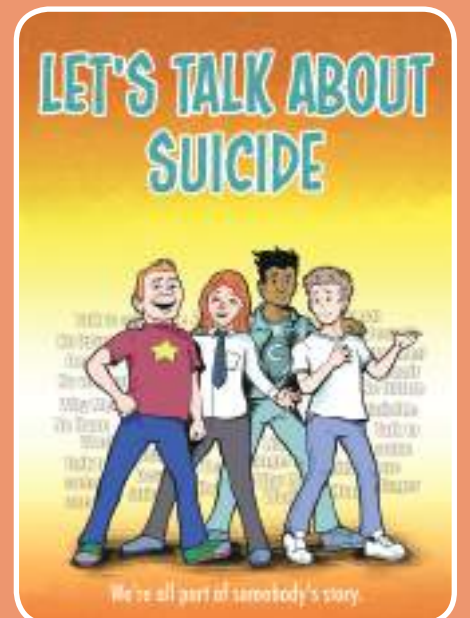
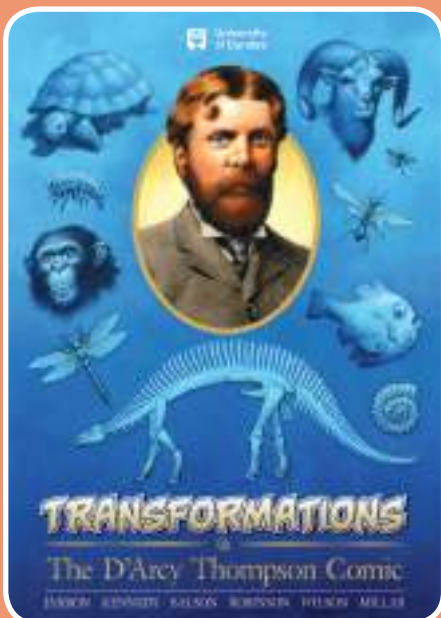
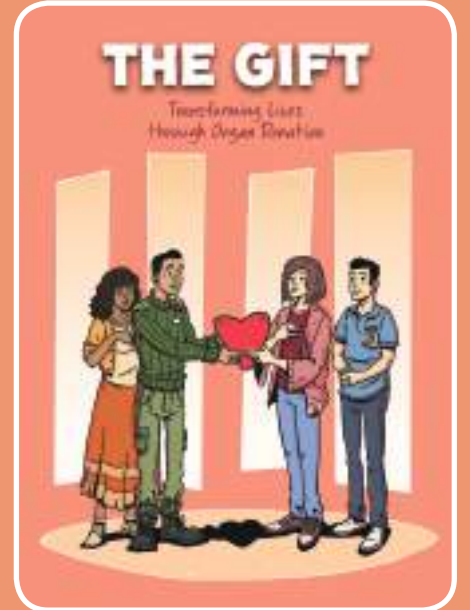


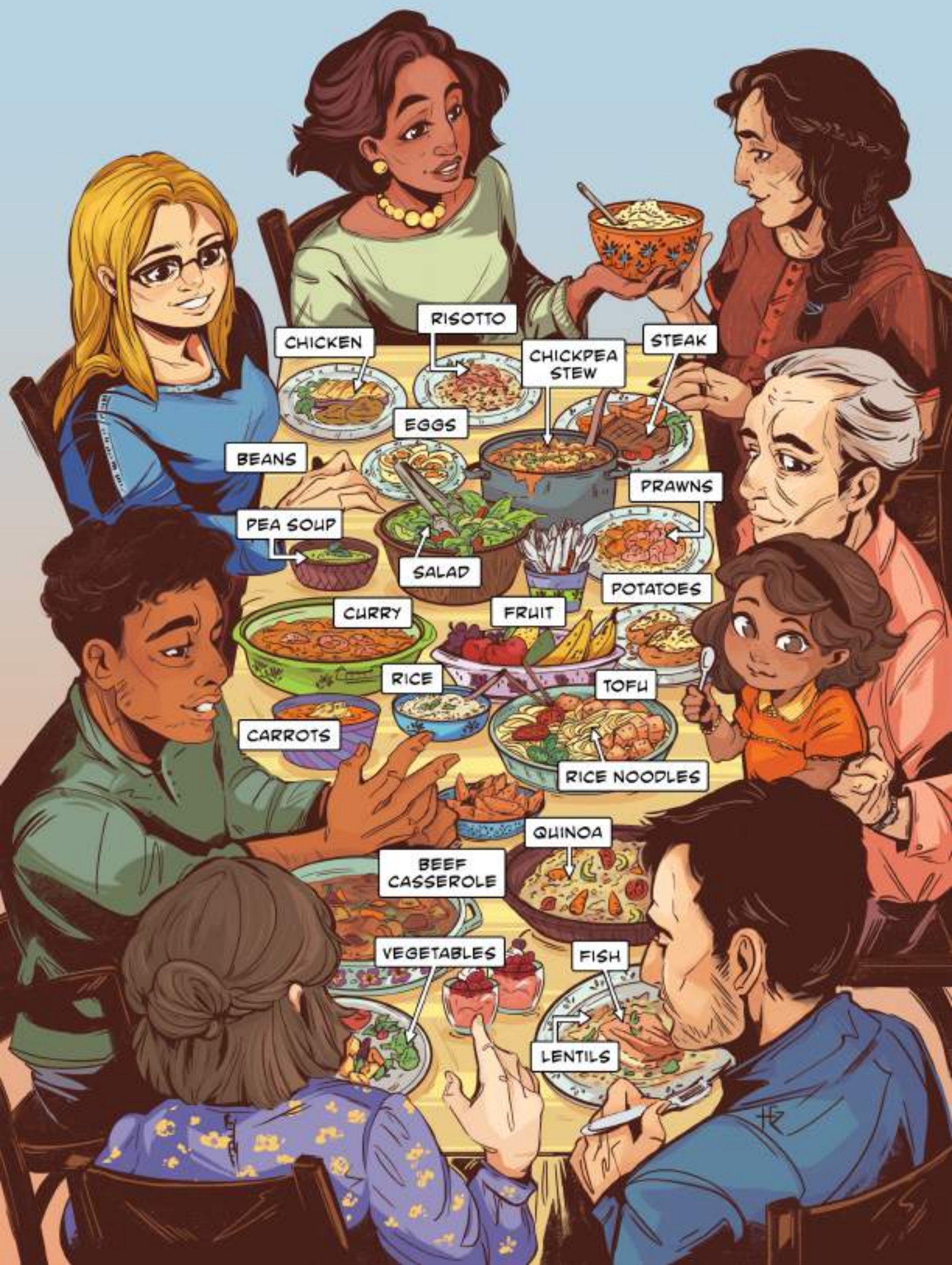
Letty Wilson is a comic artist and illustrator from the Scottish Highlands, currently working in Glasgow. Her recent work includes illustrations for Choose-Your-Own-Path book *Into the Dungeon*, and contributions to anthologies including BHP and 404 Ink's *We Shall Fight Until We Win*, and Dark Horse's *Secret Loves of Geeks*. You can see more of her work at toadlett.com.



Myles Fitt is Scotland Lead for Coeliac UK, the charity which supports people with coeliac disease and those who need to eat gluten free. He also has a personal interest in coeliac disease as his 10 year old daughter was diagnosed with the condition as a baby.

MORE COMICS BY DUNDEE COMICS CREATIVE SPACE





CHICKEN

RISOTTO

CHICKPEA STEW

STEAK

EGGS

BEANS

PRAWNS

PEA SOUP

SALAD

POTATOES

CURRY

FRUIT

RICE

TOFU

CARROTS

RICE NOODLES

QUINOA

BEEF
CASSEROLE

VEGETABLES

FISH

LENTILS